Opportunities for *PLANNING AND CONSTRUCTING* Medical— Mental Retardation— and Other Health Facilities

Proceedings
1964 Annual Conference of the Surgeon General, Public Health Service with the State and Territorial Hospital and Medical Facilities Survey and Construction Authorities
November 13–14, 1964—Washington, D.C.

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Public Health Service
Division of Hospital and Medical Facilities
Washington, D.C. 20201

Public Health Service Publication No. 930-F-6

May 1965

For sale by the Superintendent of Documents, U.S. Government Printing Office
Washington, D.C., 20402 - Price 40 cents

FOREWORD

This publication presents the proceedings of the annual conference of the Surgeon General of the Public Health Service with the State and Territorial Hill-Burton Hospital Construction Authorities which was held in Washington, D.C., November 13-14, 1964.

An annual event since 1947, these conferences have been a vital factor in the advancement of improved health facilities throughout the Nation. In addition, they have helped to maintain balanced intergovernmental relationships needed in the development of vigorous and current health facility programs.

A feature of the conference was a combined session on November 14 with State and Federal authorities responsible for developing programs for the construction of facilities for the mentally retarded.

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M. — ADJOURNMENT

1964 - A LANDMARK YEAR FOR HEALTH FACILITY PROGRAMS

Surgeon General Luther L. Terry

Good morning and welcome to you all. Certainly it is nice to have you here for our annual meeting of the Hill-Burton agency heads with the Public Heal Service. Many of you have been here over the past few days participating in ou annual meeting of the Service and the Children's Bureau with the State and Terri- torial health officers. As a matter of fact, all but six of the State Hill-Burton authorities are also State health directors so that there is more than a slight degre of coincidence there.

Others in attendance this morning are the State Hill-Burton agency progran directors and our Hill-Burton program directors from our regional offices. We are also pleased to have with us this morning a few of the representatives of the pro- grams for the mentally retarded who will be meeting jointly with this group to- morrow. Saturday morning's session, as you know, will be devoted entirely to th subject of mental retardation; and, as you will note from your program, a panel discussion has been planned which should be particularly interesting to all of you.

Since the outset of the program, our annual conferences have consisted of working meetings to explore health facility needs. We find a close relationship to the major health problems and the goals at hand. These conferences have effectively demonstrated State and Federal partnership in policy determination and in decision making. I feel that these conferences are important in terms of main- taining the balance of intergovernmental relationships and to assure the public health programs of vigor and current appropriateness and interest.

contributions that you have made over a period of several years in helping us formulate the legislative proposals which were largely enacted and which will serve to meet some of these needs which have been, we think, real deficiences in the Hill-Burton program. During the past year also, three new programs have been assigned to our Division of Hospital and Medical Facilities which have resulted from this new legislation. Under these new enactments, construction grants will be provided, as you know, for educational facilities for the health professions under the Health Professions Education Assistance Act. In addition, there are provisions for the mentally retarded which are coupled with our programs, and, thirdly, the comprehensive mental health centers. In addition to this, the Nurse Training Act of 1964 is still another piece of landmark legislation in which this Division will play a part. So that I think you can see these new programs will provide a broader framework in which to plan more adequately for the community's overall needs. At the same time, I think all of you realize that this multiplicity of construction and related programs certainly complicates many of our activities and many of our responsibilities, when one considers that any proposal involving Hill-Burton funds could, in addition, possibly involve at least two, three, or four other programs.

You at the State level as well as we at the Federal level have a serious responsibility in terms of meeting these needs in order that we can help our communities and our States provide the facilities which are necessary for the comprehensive health care which is our goal. Since the beginning of the Hill-Burton program in 1946, there have been eight legislative measures passed which have affected this program; and each new piece of legislation has meant added responsibilities for the program, and in addition to that other changes are taking place which will affect our programs and responsibilities.

This summer I had an opportunity, with our Urban Health Planning Committee representation from the Public Health Service, to visit in the Soviet Union and in several of the Western European countries. I think those of us, for instance, who had the opportunity to spend some time in the Soviet Union felt that it was a most useful and helpful experience. On the other hand, I can assure you that from the standpoint of the facilities, even the newer facilities certainly are not comparable at all to those existing generally throughout this country, and even in the Scandinavian countries. I was greatly assured in terms of seeing many of the developments that are going on there since their programs are in general very progressive. At the same time I was pleased to see, in general, how well I thought our programs, our activities, our facilities compared with theirs, so that I think we can say up to this time that we have done a good job. We've recognized deficiencies in our overall program, but we have done a good job. Yet there is much more to be done. There is much more both in terms of quantity and quality. I think, however, that I can rest assured in my own mind on the demonstration of our State and local authorities in working with us that we have demonstrated throughout this country clearly the ability to handle such developments and to move progressively with them.

In closing, I would like to assure you that from the standpoint of the Public Health Service we are most anxious to continue this close and cooperative working relationship, because I am sure that as we move along some of our problems are going to be more complicated. But whether they are more simple or more complicated, they will be solved more effectively if we work cooperatively together. It is in that direction I intend to move and expect the staff of the Public Health Service to move.

OPPORTUNITIES AHEAD

Assistant Surgeon General Harald M. Graning
Chief, Division of Hospital and Medical Facilities

It was one year ago this month that I met with you for the first time. The place, as you recall, was Kansas City. Our discussions mainly revolved around new programs just getting started. We also spoke of some changes expected to be made through newly proposed amendments to Hill-Burton.

Today, on this Friday the 13th--one year later--we find there is much for which to be thankful. Although the year has been fraught with more than the usual number of problems and frustrations, I am sure we would all agree that it WAS a good year. A year of victory. A year in which ideas for which you had fought for many years finally reached fruition in the form of legislation.

Now that we have been given the nod to go ahead, there's hardly time to stop and count our blessings. Instead, we are finding that all of our thoughts and energy must be directed to the many tasks which now face us--the many opportunities ahead.

When I told one member of my staff that I had chosen "Opportunities Ahead" as the topic for my talk, I was warned to be cautious since the meeting date had been set for Friday the 13th! I reminded my friend of my Norwegian heritage and that Norsemen considered Friday as lucky. This prompted a bit of research. In very short order I was advised that according to Norse myth, Friday is named for Frigg, the Norse goddess of the sky. Frigg, along with the constellation Orion, share full knowledge of the fate of the world and dominion in heaven. Certainly a day named for such an important goddess would be anything but unlucky!

Another note of interest was that Friday was the festival day of the Norse goddess Freya. The day was lucky if observed in the proper manner, but unlucky if the goddess was not worshipped and one followed his own pursuits--whatever that means!

Delving further into this subject we found that the Norsemen were not alone in their belief that Friday was a lucky day. This belief also existed among the Moslems who chose Friday as their day of worship.

On the other side of the coin, we find considerable uncertainty as to why Friday is an unlucky day. A source at the Haskin Information Bureau here advised us that the unluckiness of Friday among Christians goes back to Good Friday because of the crucifixion....Friday was also considered unlucky by Buddhists, Brahmins and the ancient Romans, but we were unable to uncover any reason for this.

As to why 13 is an unlucky number, the origins are also uncertain. It is felt by many who delve in such matters that the number 13 goes back to the Last Supper (the night before Good Friday) when 13 were present. Still another source cites another legend regarding 13 as a bad luck omen. In Scandinavian mythology there were 12 demigods and then Loki--spelled L-O-K-I--came among them, making 13. He was cruel, evil, and the origin of human misfortunes.

But, be that as it may, the number 13 should be considered anything but unlucky for the Hill-Burton program. It was on August 13, 1946, that the original Hill-Burton legislation was signed into law, and next year, we will be celebrating our 19th anniversary on Friday the 13th.

1964: A Year of Change and Growth

Each of you, I am sure, will agree that keeping abreast of all the new programs and changes over the past year has been difficult. And, as past experience has taught us, there is no gain without pain. We've all had to roll up our sleeves and put forth much extra effort. In the coming year we can expect our commitments to be even greater than in the past. But added tasks mean added opportunities which brings to mind that frequently heard expression: "An optimist sees an opportunity in every problem; a pessimist sees a problem in every opportunity!" During the time that's been allotted me this morning I would like to examine some of these opportunities and explore some methods for achieving our goals.

If I may borrow an expression recently used by our President, our "horizons are unlimited." At least they appear so both in terms of correcting the deficiencies which now exist and in providing a framework for filling the anticipated needs of the years ahead.

In striving to attain these two overriding objectives we hope we will not limit ourselves either in approach or effort. When old methods are no longer applicable we must look for a fresh, imaginative, bold approach. This is particularly true in a program as dynamic and fast-moving as Hill-Burton.

Perhaps out of the habit of 18 years we will continue to refer to our program as Hill-Burton--even though during the past year we have outgrown our name. The new legislation which revises and extends Hill-Burton is becoming known as the Hill-Harris amendments. And to further complicate matters, the program, after extended courtships covering many years duration, found itself wedded to three new construction efforts: First, aid for educational facilities for the health professions; second, mental retardation; and third, mental health. As with most marriages, the first year was one of readjustment--a state which no doubt will continue for a while. None of the brides brought a dowry along. But in recent months each of our newly acquired partners has become self-supporting.

Now that our budgetary problems are being ironed out, there is every indication that our household will be a happy one. This optimism is based in large measure on the high degree of compatibility among all four parties concerned. Already we have come to recognize that the Division's total program is greater than the sum of its parts.

Opportunities

All of which brings us back to the subject "Opportunities Ahead." What are our opportunities and how might we best fulfill them?

The opportunities facing us can, broadly speaking, be placed in two categories: Planning and research. While our opportunities have no boundary lines in either of these areas, in one sense they might all be welded together into our all-encompassing opportunity: to make available all needed facilities and services to all people in the community. In making the most of this opportunity we must continually be mindful of our responsibility to foster better patient care in up-to-date facilities which are operated at maximum efficiency. To view this on a practical basis, we must have manpower, money, and motive--but not necessarily in that order. Motive has been with us for many years. As a result of revised Hill-Burton legislation, money is soon to be made available to aid States in the administration of programs. This means that in very short order we should begin to make inroads into getting the manpower so badly needed to effectively carry out planning functions.

PLANNING

And now let us look at planning--the first of our two broad categories. Hill-Burton, as you know, cut its baby teeth on the concept of planning and ever since has clung to this philosophy quite tenaciously--much like the "Peanuts" cartoon character, Linus, and his blanket. Frankly, it IS a concept that we SHOULD hold on to--but wisely.

While the "why's" of planning are the same now as they were 18 years ago, it's the "how's" that have undergone change. All of us have, from time to time, found change both disruptive and difficult to live with while it occurs. Nevertheless, the dynamic progress which has been made in the program over the years has come about as a result of your unusual talent to adapt to change. We have found that change stimulates our desire to maximize our efforts and assume a fresh approach. Change creates new opportunities, new horizons, new chances for service.

We have learned that what might have proved successful in one era under one set of ground rules will not necessarily apply at a later period. Even the animal world--other than man, that is--has had to cope with change. For example, the rabbit of the forest remains stark still as a defense mechanism against impending danger. But if he were to use this mechanism while in the middle of a highway he would soon be a dead rabbit!

And so we ask what are some of these changing ground rules? How can we make the most of these opportunities which are now before us? There are seven ways I would like to explore with you:

First: By more definitive analysis of our health facility needs.

Second: By elevating and enforcing State licensure requirements in terms of not only hospital structure but their maintenance and efficient operation as well.

Third: By encouraging coordinated health facility planning, or at least understanding, by all units of State government that have any responsibilities in the field.

Fourth: By providing leadership in the development of areawide planning agencies.

Fifth: By encouraging the modernization of facilities where such needs exist.

Sixth: By stimulating the further development of educational programs for those involved in hospital operation, organization, administration, and maintenance.

Seventh: By continuing to further the concept of preventive care and the need for carrying out such programs in a proper setting: the public health center.

Definitive Planning

Beginning with fiscal year 1966, determination of bed need will be based on utilization experience in the population concerned and other factors such as occupancy.

The new regulations, which you will be discussing in greater detail at your group sessions, reflect not only revisions made in our new legislation but also the recommendations of the same ad hoc committee (previously mentioned) which, for the past several years, has been examining ways of updating our procedures and methodology. It took much courage...and, above all, a deep sense of responsibility...to face the fact that our old planning methods were badly in need of refinement--that a wide array of factors must be carefully evaluated before passing judgment on just what is needed from the standpoint of total beds and modernization.

Representatives of this committee are planning a number of regional orientation sessions in various sections of the Nation during the next several months. You will be hearing more about this in a very short time. In fact, the first of such conferences will be held in Atlanta next week and the staff of a number of State agencies will be attending.

State Licensure Requirements

My second point is the growing need to elevate and enforce State licensure requirements--not only in terms of hospital structure and maintenance but also operation and administration.

Here, again, this need is reflected by a clause incorporated in the Hill-Harris amendments. The State agency is given specific responsibility for establishing and enforcing standards of maintenance and operation for Hill-Burton-aided hospitals.

Standard-setting has been a requirement of Hill-Burton since its outset, however, this is the first year that there has been an enforcement clause. While we feel that State licensure provisions have helped elevate the quality of hospital structures to a large degree, there are still many missing parts in the total licensure picture.

One of our staff members undertook a comparative study of licensure requirements early this year. Her analysis uncovered a wide disparity of requirements among the States. Some were found to still be operating on standards set up as far back as the early Hill-Burton days.

Because of limited staff and unlimited workload, many State agencies have not been able to carry out as thorough a job as they felt was actually needed. For many, only the minimum requirements noted in the regulations were matters which could be given their attention.

When deficiencies are found and corrective measures are recommended, the State agencies can be of great service to the hospital by providing guidance regarding improvements which should be undertaken. These improvements should relate not only to the physical structure and equipment, but to methods for more efficient operation as well.

Reports we have received from various States indicate an interest in strengthening licensure programs, and we are hopeful that on the Federal level we will be able to provide more assistance in this regard than was possible in the past. Although Hill-Burton's grant program does not include the operation and administration of facilities, we do have a responsibility to provide guidance wherever it might be needed in the interest of improving our Nation's hospitals.

Coordination Among Planning Groups

The third responsibility is your role as a unifying force in coordinating the planning by all units of State government that have a responsibility in the health facility field.

In many States, Hill-Burton agencies will not be designated to administer the construction grant programs for comprehensive mental health centers and for community facilities for the mentally retarded provided by Public Law 88-164. This, however, does not mean that you will not have a role to perform in connection with these two programs. The newly appointed planning groups will find there is much to be learned from your past experience. You will undoubtedly find ways in which you can each be helpful to one another--particularly from the standpoint of exchanging ideas. You can serve as the unifying force for those groups which are concerned with only fragmentary portions of the planning picture. In this connection, it is extremely important that at the outset a basic understanding be reached covering all areas of mutual interest. And, above all, establish lines of communication so that there will be a continual flow of information among all planning bodies.

Modernization

Perhaps the most significant opportunity and responsibility is point five which involves the need for appraising and encouraging the modernization of obsolete health facilities.

Although the amounts do not begin to approximate the reported need, the law authorizes the appropriation of $20 million for fiscal 1966; $35 million for 1967; $50 million for 1968; and $55 million for 1969. State Agencies will be expected to submit a plan covering modernization needs by January 1966. All types of health facilities are eligible for consideration. No modernization funds may be utilized until the plan for modernization has been submitted and approved.

The methodologies that have been developed for the appraisal of modernization need will be discussed in detail in the discussion sessions this afternoon. They represent the work of an ad hoc committee and have been field-tested by some State agencies.

Educational Programs

The sixth opportunity which we share is that of working toward more efficient hospital organization, operation, administration, and maintenance. An example of an activity in this area is the conference cosponsored by the Division of Hospital and Medical Facilities and the University of Colorado Medical Center held in Denver last month for hospital chiefs of staff. Discussions centered on the functions, responsibilities, and relationships of chiefs of medical staffs. Registration totaled 343 with participants drawn from many States throughout the Nation and from Canada. There was such an enthusiastic response to the program that recommendations were made that similar conferences be held on a regional basis.

Our Division has had repeated evidence of the need for encouraging preventive maintenance programs in hospitals that have been built and we are currently exploring ways in which this could best be accomplished.

Public Health Centers

The seventh opportunity is that of doing a better job in planning for and constructing public health centers. This group certainly does not need to be reminded of the premium which should be placed on the concept of preventive care by those responsible for building health facilities in a community. Unfortunately many sections of the Nation have not made adequate provision for public health centers, and I would urge that more serious consideration be given to meeting this need.

You could undoubtedly add to the seven planning opportunities I have mentioned, but these must suffice for the moment.

RESEARCH

The second broad area of opportunities is that of research.

Over the years, to most people Hill-Burton has been associated with construction projects. All too frequently research and demonstration have been relegated to a back seat position.

As in the original legislation, the recently enacted amendments still cite as one of the purposes of the Act, and I quote, "to furnish adequate hospital, clinic, or similar services to all the people." Another purpose reads as follows: "to promote research, experiments, and demonstration relating to the effective development and utilization of hospital, clinic, or similar services, facilities, and resources, and to promote the coordination of such research, experiments, and demonstrations and the useful application of their results."

Everyone agrees that research is a good thing...that research is needed to find the solution to some of our most troublesome complaints against hospitals and health services...that our constantly developing new challenges require the depth of attention which can best be given through research and demonstration. The opportunities in this area are greater than at any time in our history.

All the theories and approaches to planning and the furnishing of "adequate ...services" to all the people fall by the wayside without knowledge, understanding evaluation, and guidance toward their logical implementation. Some examples of important areas needing additional investigative effort include the general organization and functions of hospitals; the most effective and efficient use of personnel; costs; communications within and among hospitals; educational responsibilities both to the staff as well as to the patient; patterns and quality of care; services of various departments, including the outpatient department; and general aspects of administration.

This is only a partial listing of the problem areas which require far more research and investigation. A more comprehensive listing appears in our latest Hill-Burton publication just off the press today entitled, "Hospital Administrative Research." This publication also presents a complete listing of all of our research projects thus far undertaken with a one-paragraph description of each and the publications resulting from these projects.

A review of some of these projects shows, among other things, a growing trend to find new uses for the computer as a tool in solving a wide range of hospital problems. So far more than $3 million has been awarded for work in almost two dozen projects.

It appears that there's very little within the realm of imagination that can't be fed into a computer and with good results. Last January's issue of the AHA journal, "Hospitals", was devoted to that subject. The lead article by Alfonso Pia of Salt Lake City describes the potential uses of automatic data processing and stresses the fact that "no other method holds an equal promise for the future, especially with the introduction of more detailed data requirements and controls."

One of the more unique computer projects that Hill-Burton has sponsored has to do with menu planning. In less time than it takes to make a cup of instant coffee it has been found possible to prepare the menu for a complete meal --by computer. In less than 40 seconds per menu, the electronic brain can schedule, for a period of days or weeks, menus which satisfy daily dietary, taste, and cost requirements--or any other combination of requirements. In resolving these menu-planning problems via computer, dietitians are given more time to improve the quality of their work, spend more time in patient education, increase their value to the hospital, and aid in reducing food costs by 25 to 30 percent.

A word of caution may be appropriate with reference to computers. The recent phenomenal performance in predicting final election results when only a small percentage of votes had been tabulated was the culmination of 4 years of hard work in programing. Opportunities for using electronic information retrieval systems and computers are being extolled by many who have devised various procedures. Joint and careful consideration of what data are the most desirable and meaningful will prevent many false starts. The importance of being sure of the validity of initial observations appears to transcend all other considerations in this rapidly developing field. Rental of computer time from some centrally operated group makes mathematical genius available to all who have good initial observations.

There are three opportunities in the research area in which the States can perform a unique and important service:

Conduct Research

First, there is the opportunity for the State Health Department, as a public agency, to undertake a research project either on its own or in collaboration with another agency or institution. Examples of such projects were those carried out several years ago by Dr. Knudsen in Minnesota and Dr. Williams in Georgia, and a project now being conducted by the California State Department of Health under the direction of Daniel L. Drossness. The Minnesota project was a demonstration and study for improving patient care. A team of medical and paramedical consultants were engaged to work as a team under the guidance of an advisory committee and State Health Department staff members. Team members worked in hospitals and related institutions to demonstrate methods for improving medical care. Emphasis was placed on refresher courses, increasing services to the public and

recruiting additional hospital personnel. Of primary concern were such areas as nursing, anesthesia, dietetics, medical records, medical technology, and physica therapy....The Georgia study was a cooperative undertaking with a State colleg to train qualified persons as food service supervisors....The project now being conducted in California is to determine the most efficient method for the collect and use of hospital utilization data on a statewide basis.

Encourage Research

The second opportunity lies in your role to encourage hospitals and other nonprofit institutions to carry out research and demonstration. There no doubt is many a novel idea that has never taken hold, nor--for that matter--even gotten off the ground, for lack of finances. As hospital construction authorities and program directors you have contacts with many hospital people in your States. You, therefore, are in an excellent position to know of problems facing institut

Frequently we have found that the problems of one hospital are common t many other facilities. Should you feel that a research proposal has sufficient merit and falls within the purview of our program, then you can be of real servi to advise the hospital of our research program and suggest that they explore furth with us the merits of their proposed undertaking.

Communicate Findings

Your third opportunity is in the area of communications.

The results of many of our projects, particularly those which are intramur in nature, ultimately appear in Hill-Burton publications or as articles in professi journals. Examples of the types of research which could find universal applicati relate to a wide range of subjects such as noise and lighting in hospitals, outpat services, hospital nurseries, centralized services, hospital utilization, and progre patient care. In regard to the latter, we now have a movie on the subject whi you will see this morning. You will be able to borrow it for scheduled showings no charge, and may purchase prints if you so desire. Here is an excellent oppo tunity to promote a concept which has been endorsed with much enthusiasm by hundreds of hospitals around the Nation.

In regard to capitalizing to the fullest on the guide materials that we se you, you might find it worthwhile to re-examine your distribution methods and explore ways of reaching all persons who could benefit from the use of these ma This would be one area in which the health educator in your Department could b helpful.

In closing, on this Friday the 13th I think it might be fitting to note that we must take every precaution in our planning efforts to, wherever possible, eliminate the element of chance. At the same time, however, our planning should be sufficiently flexible to allow for the unusual or unexpected.

If there be such a thing as luck, then those of us here today can feel most fortunate for the new opportunities for service which have been handed us during the past year. While supernatural influences may be a subject for debate, of this we are sure: that the legislation which has opened new doors to opportunity for all of us did not come about by mere chance. It represented the culmination of many years of effort on the part of people in many fields. We are grateful for the role that many of you have played in making this possible.

Appropos of my remarks today, I would like to close with the following quotation by Winston Churchill:

"The destiny of mankind is not decided by material computation. When great causes are on the move in the world...we learn that we are spirits, not animals, and that something is going on in space and time, and beyond space and time, which, whether we like it or not, spells duty."

INTERFACES OF MENTAL RETARDATION

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The interfaces of mental retardation are vast and many. They exist at every age in an individual's life and at all socioeconomic levels. They affect both the biological and social structures of an individual's life. Although not a disease, mental retardation may be associated with a disease, it may accompany a disease, or it may result from disease. It has so many protean manifestations that it can only be described as a functional difference from normality.

Mental retardation has been defined as a degree of mental inadequacy incompatible with adjustment at maturity.

The American Association on Mental Deficiency defines mental retardation as subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior. Added to this is the fact that the interference with adaptive behavior may be either because the retarded cannot become economically independent or because his behavior is not socially acceptable.

Most of the people working in the field of mental retardation will add to these wide definitions of retardation the fact that retardates have a poor sense of the passage of time, that they lack judgment, and many would say they lack what we usually call common sense.

The causes of retardation range from
and conditions resulting from multiple inferio
factors of familial defective groups and some environmental factors.

These causes are listed as follows:

CAUSES OF RETARDATION[1]:

Prenatal:
Genetic factors
Conditions resulting from multiple inferior genes
The physiologic, subcultural, or familial defective group (also

*Former member of the White House Staff, Deputy Assistant to the President for Mental Retardation.

[1]Modification of chart in chapter on "Mental Subnormality," by Harrie R. Chamberlin, M.D., in Pediatric Neurology, edited by Thomas W. Farmer, p. 134. Hoeber Medical Division, Harper & Row, Publishers, New York, N.Y., 1964.

in part environmental)
Conditions due to mutant genes
Autosomal dominant
Ectodermoses
Tuberous sclerosis
Neurofibromatosis
Question of some forms of hypertelorism
Autosomal recessive or sex-linked recessive
PKU
Hartnups Disease
Wilsons (hepatolenticular degeneration) Disease
Galactosemia
Gargoylism (mucopolysaccharides)
Lipidoses
Tay-Sachs, Bielschowsky's, Spielmeyer-Vogt, and Kufs Disease
Nieman-Pick
Gaucher's
Non-endemic goitrous cretinism
Congenital nonhemolytic jaundice with kernicterus (glucuronyl transferase defect)

The inheritance of many other metabolic problems is not yet identified, but recessive genetic patterns suspected include:

Leucine-sensitive hypoglycemia
Histidinemia
Hyperprolinemia
Pyridoxine-deficiency
Infantile hypercalcemia (may also be due to over dosage of mo. with D.)
Pseudohypoparathyroidism
Cerebro-oculo-renal syndrome of Lowe
Maple syrup urine disease
Progressive leukoencephalopathies

Cranial defects such as microcephaly and a question of craniostenosis and also hypertelorism.

Chromosomal Aberrations[2]
Mongolism - Trisomy 21 or 22
(1 in 600) Translocation of part of 21 out of 13, 14, or 15 or possibly 21 or 22 (patients have only 46 chromosomes and their Mothers tend to be young.) Many relatives may have only 45 chromosomes.
Mosaicism with more than one cell line
e.g. 45 - 46 - 47

[2]Ibid., Page 134, 135.

Trisomy other than 21 -
17 or 18)
13, 14, or 15) Multiple congenital defects (CNS, cardiac, and skeletal)

Abnormalities of sex chromosomes
XXX - Klinefelter's (1 in @ 400 males - mild retardation)
XO - With 45 chromosomes (Turner's Syndrome)
XXX - (Super females with 2 sex chromatin bodies - one in @ 800 live births) Many are mildly retarded.

Environmental factors affecting the fetus
Radiation
Maternal infection
Conditions occasionally associated with maternal malnutrition
Toxemia
Prematurity
Maternal ingestion of drugs
Maternal thyroid deficiency
Others
Prenatal group of unknown etiology (undifferentiated)

Perinatal:
Asphyxia
Trauma
Hyperbilirubinemia (in part prenatally determined)

Postnatal:
Central nervous system infections and their sequelae
Cerebral trauma
Dehydration in infancy
Idiopathic hypoglycemia
Poisonings
Others

Then, of course, there is the vast group of unknown and undifferentiated types due to some unknown and undifferentiated prenatal causes.

Perinatal causes include asphyxia, trauma, and anemia. Postnatal causes include central nervous system infection and the results of this, measles, and so on; damage to the brain itself, directly or indirectly; severe dehydration, hypoglycemia, poisonings, and then a multiple listing of other things.

Scope of Problem: The incidence of mental retardation is now commonly accepted as approximately 3 percent of our population. This is about 5.6 million human beings, a group of people for whom we must do something and with whom we must do something and large enough to merit our very serious consideration.

Each year approximately 126,000 more retardates come into the population. Children are born who will be retarded and recognized as such early in life or will become retarded at sometime during their life.

It must be noted and emphasized, however, that this figure of 5.6 million does not encompass all those people who are functioning at subnormal levels because of emotional or social factors that interfere at some point or another with their normal innate intelligence.

The incidence of retardation varies to some degree with region or locality, it varies with genetic factors, it varies with social and cultural factors, it varies with educational and public health factors. It also varies with age, and this, in part, reflects our inability to spot the mildly and even some of the moderately retarded individuals early in life. It also reflects the fact that many of the mildly retarded disappear back into the population after the competitive years of school are over. Some studies have shown variations from about two-tenths of a percent of the age group from birth to one year, rising slowly on up to 2 percent in the five-year period, 6 percent at six years, 8 percent in the period between 10 and 13 years, and then dropping down again to 2 percent of the population at 17 years.

Types of Retardates: Many people, when you say to them you work in retardation or you work with mentally retarded children, say, "Well, how can you stand it? These are such unusual looking people, they have so many defects." They think of an odd looking person when they hear about a retardate. But this is obviously not so since many retardates are quite normal physically and lack only the intellectual and social developmental factors.

The old terms of moron and imbecile and idiot, now badly connotated, are no longer used by those in the field, but remain in the minds of many people.

The terms mild, moderate, severe, and profound are used now to describe the ranges of retardation. The mild have IQ's of 55 to 69; the moderate between 40 and 54; the severe between 25 and 39; and the profoundly retarded are those whose IQ's are below 25. These figures are based on an average normal IQ of 90 to 110. Our instruments are imperfect. Our psychological tests do not really find out all the things we want to know at the lower levels of the curve. Yet this is, as we stand at this point, one of the few so-called objective means of measuring retardation for purposes of classification.

In terms of distribution among the group of retardates, about 85 percent are in the mild group; that is, with IQ's above 50. The moderately retarded are probably somewhere in the range of 12 percent of the total retarded population. The severely and profoundly, those needing the greatest amount of care, represent only 3 to 3-1/2 percent.

Of the 5.5 to 5.6 million or more persons who are not able to make satisfactory occupational or social adjustments, only approximately 200,000 are now getting total care in public or private institutions for the mentally retarded. This leaves the vast majority of these people in their own homes and in their own communities needing the whole spectrum of services and support that the President's Panel on Mental Retardation aptly calls the "continuum of care." It is for these retarded human beings who have a variety of disabilities, and needs, that we must plan and build carefully, comprehensively, and cooperatively.

It would seem important for this group to explore briefly the relationship of the retarded and the total population and, more specifically, the relationships of the retarded to their family and to their community.

These relationships depend on the degree or type of retardation. They depend on the presence or absence of physical or structural defects. They depend on the presence or absence of neuromuscular or special sensory handicaps, and these handicaps in turn vary in their severity and this also affects the relationship of the retarded.

Further, the degree to which any retardate can establish a satisfactory relationship with his community will depend to a large extent on the availability and excellence of local resources, on the degree of public awareness and understanding of the problems of mental retardation, and the ease with which early evaluation and early placement in the proper channel for care, for training, or for education is made.

One additional but omnipresent variable is the availability of economic support for the retarded, either from his family, from his community, or from other sources.

It can be seen then that the interfaces between the developmentally retarded and other human beings are numerous and depend, in turn, on a large number of variables. In addition to these interpersonal interfaces there are a number of interrelationships between retardation and many other aspects of society. Those that are more or less directly related to the severely and profoundly retarded are primarily early evaluation and diagnosis; proper care, either at home or away from home; the economic problems related to the impact of the retarded on the family and the community; the relationship of the severely and the profoundly retarded to the laws that deal with civil and social rights, and the laws that deal with eugenics.

For the mildly and moderately retarded the interfaces are considerably greater in number. There is, depending on the degree of mild or moderate retardation and the resources of the family, a wide spectrum of type and amount of care needed. The training and education of these persons should be started as early as diagnosis and evaluation have been accomplished, and in most cases, it must be continued long beyond the age at which secondary education is usually completed by normal individuals. The provision of prevocational and vocational training and an adequate system of job protection must be made.

There are many therapeutic programs possible for the developmentally retarded. Many of these show great promise and yet, except for very few places in our country, these therapeutic programs for the mentally retarded lack both support and facilities.

Economic Interrelationships: There is one more very important interface of developmental retardation in society. It can be called the economic interrelationship between society and retardation in that it deals with the cost of retardation. However, this cost is, as in so many things, not easily figured just in dollars. The estimate in dollars varies and it is hard to tie down good, solid figures as to how much mental retardation costs the United States each year. Perhaps as much as $1 billion to $1-1/2 billion is spent on this support which includes buildings and maintenance and staffing of public and private institutions, special health and welfare needs of the retarded, the extra costs

of special education, and the out-of-pocket expenses to families for all the different therapies such as physical, medical, psychological, and speech which the retarded needs in greater amount than the normal.

All of these costs may add up to a billion or a billion and a half dollars. Add to this cost the loss to the gross national product of the large percentage of the retardates who could do something productive if given a place in which to do it and some early training and help in making some social adjustment. The loss to the gross national product has been estimated at between 4 and 4-1/2 billion dollars. Thus the total cost of retardation is currently estimated by knowledgeable experts at something around 5 to 6 billion dollars a year in this country alone.

Put this in another way, the current expensive plans for construction and services and programs for the retarded have as one of their primary goals the development of facilities and programs that will decrease the overall cost of care and concurrently shorten the time in which total care is necessary. It will help all retardates directly and also serve to develop all those retardates possible to that level of potential at which they can in some way contribute to society rather than spend their lives just taking.

The other dimensions of the cost of retardation cannot be estimated in dollars nor be conceptualized as easily as the out-of-pocket expenses to families, to States, and to the Nation. They are: the chronic sorrow of the parents; the frequent disruption of marriages; the adverse social and emotional effect on parents, siblings, and relatives; and the anti-social emotional reactions of the retardates themselves. How can these be measured or dollar costs assessed for them?

Action Required: The time to do something is today, now, this year, next year, and in the immediately following years. We must do many new things and many better things to combat developmental retardation. There are so many interfaces, there are so many problems, and there are so many needs. There are so few professionals and so few skilled nonprofessionals working in the field. There are so few facilities, overall, and there are so few known facts.

There is so much work to be done in research, in training and in education, in diagnosis and evaluation, in treatment and therapy for the retarded and in training of manpower for work with the retarded. Yet, in spite of all these seemingly insuperable obstacles, we must continue to work and get on with the job.

Some of the needed facilities for mental retardation must be planned for research, for evaluation and diagnosis, for care at all levels, for therapy, for training of the retardate, for education of the retardate, for habilitation or

rehabilitation and job placement, for sheltered work, for sheltered living, and for sheltered recreation. And finally, perhaps the most important thing, for training of professionals and skilled nonprofessionals for work with the mentally retarded. If we have one major area in which we have a great lack, it is perhaps the latter.

This is not really an exhaustive list but I think these are some of the highlights.

Research encompasses a great many things besides test tubes, laboratories, and experimental animals. We know some things about learning theory and we have some theories about learning. We know some high points in the neuromuscular, social and emotional development of the human being but we need a lot more of the details.

We know a few things about the etiology of developmental retardation but we are far from having solved the problem. We can prevent now a few types of mental retardation but we have many, many more types for which there is no prevention.

We have some kinds of care now but we have not really studied better kinds of care or new kinds of care or different ways and means of care. Most care now is provided in a fairly classic style either as 24-hour custodial care or day care, or variations of these. New methods must be developed and evaluated.

We know something about the habilitation of the retarded but not enough. We need to study that.

We know something about the social adjustment problems of retardation, but not enough. We have some ideas about better ways to educate and/or train the retarded, but not enough.

These things are partly test tube, but predominantly clinical by applied research in the world of the retarded.

Evaluation must be relatively exhaustive and in depth. It should cover
al, neurological, auditory, language, neuromuscular, and psychological
ome and the family should be evaluated by the social
h nurse.

... evaluation a knowledge of the community in which the retarded lives or will live, and a knowledge of the community's resources, and then you can produce a plan for care, for training or for education. And finally, these things all put together will bring about the greatest degree of total habilitation possible for any child with any given potential.

The services needed by the retarded vary with age and with the degree of retardation. Care from infancy to age 8 or so must include diagnosis and evaluation; hospitalization for prolonged observation to allow a better evaluation; hospitalization for therapy and training or in some instances, to relieve totally destructive intrafamilial situations. Other infants and young children with developmental retardation may need only day care for therapy, training, or to relieve family problems.

From ages 6 to 8 up to adulthood, custodial day care may be needed for the untrainables, the severely and profoundly retarded who can be kept in their own homes at night and on weekends. Some of them may require full 24-hour a day, seven days a week care.

Other needs are: special classes for trainables, educables, and slow learners; special instruction and training for those having associated handicaps; and occupational training for the trainables, educables, and slow learners.

Those from 21 on through adulthood need some facilities for custodial care. They need programs offering environmental therapy and training. Further, sheltered workshop facilities must be developed in every community where it is at all possible. Every effort should be made to get the retardate back into society in his home community as soon as possible.

Twenty-four hour care is considered classically custodial but it has many other dimensions. It includes extended diagnostic procedures, intensive treatment and training in physical therapy, speech therapy, play or group therapy, and nutritional therapy. It involves control of convulsive disorders, and care before, during, and after corrective surgery. It includes toilet training, self-dressing, and other self-care training.

Day care has not really been developed to any great degree in any area. Day care is much less expensive than 24-hour care. It can be custodial, that is, just keeping children who are retarded when their mothers work, or, if the family situation is too stressful either for the retarded or for the family; either way it works for the same end.

There is therapeutic day care for socio-cultural stimulation, for emotionally disturbed retarded children, and for the physically handicapped.

The services needed by the retarded vary also with the degree of retardation and include total care, day care, intermittent care, and home care. Home care programs provide skilled workers who can offer guidance to parents so the child can be cared for in the home.

Therapy includes medical, surgical, physical therapy and environmental therapy, nutritional therapy, developmental training therapy, speech and language therapy.

Research should include pathogenesis, neuromuscular development, types of care, social and emotional impact, and communicological or language research.

The moderately retarded need these cares.

For the mildly retarded, more must be provided in the training and education area than for the moderately retarded.

It is not possible to go into any greater detail of the kinds of care and the varieties of facilities, but it must be emphasized that retardation has a tremendous degree of heterogeneity, that the needs of the retarded are heterogeneous, and that the multiplicity of interrelationships and interfaces between the retarded and their families and their neighborhoods and their communities and their States and their Nation are tremendous. And finally, that the diversity and complexity of facilities to be developed are great.

The laws that we now have, Public Law 88-156 and Public Law 88-164, are the result of sincere and continued dedication of many, many people. They represent new hope for service and facilities for the mentally retarded and the mentally ill. They are clear in their intent and purpose. They call for State planning for programs and services and State planning for facilities.

Unfortunately, however, the laws do not specify any mechanism for interaction or coordination between the agency responsible for program and services and the agency responsible for facilities and construction. Obviously the jobs to be done are too big for any one governmental agency at whatever level. But perhaps the administrative interpretations in the regulations have made the subdivision of responsibility a bit too great.

Rules and regulations have a very real place. So does specialization of effort in government at all levels. But this machinery can become too complex. The amounts of money that will become available for community mental retardation centers, if any more than five or six are planned for any given State, will be rather modest; yet the amount of paper work, site inspection, committee review, travel and appearance at hearings, may be immense.

The laws and their administrative interpretations may not require nor demand interagency cooperation or even interagency coordination between those planning programs and those planning facilities. But common sense does demand this. This large segment of our population, the 5-1/2 million retarded, and the 15 to 20 million others directly involved in their problems--parents, siblings, relatives, and neighbors--cannot wait on protocol nor do they understand it. They cannot wait while level after level reviews the application and looks carefully to see if there is full exposure of this discipline or that discipline and looks carefully to see if there is proper and adequate inclusion of administrative control. These people want and need facilities as soon as practical and possible.

As you know, it is the responsibility of the Federal Hospital Council to make recommendations concerning construction regulations governing the types of facilities eligible for Federal aid. Individual States which know their own needs in their own areas are required to develop a plan that conforms with the general regulations prescribed under Section 133 (1) of Public Law 88-164.

A free flow of communication would help to avoid unnecessary duplication of effort by different agencies. Every effort should also be made to maintain constant cooperation and coordination between the agencies planning services and programs and those planning facility construction. Buildings that are not planned specifically for the programs and services to be housed therein are by and large impractical. The distribution of buildings throughout a State or region, when planned separately from the distribution of services, may well be impractical.

The entire impact of the legislation and the exposure and emphasis given to the problem of developmental retardation before, during, and since the legislation by the late President Kennedy, by Dr. Stafford Warren, by the Secretary's Committee, and by the special identification of persons in branches and committees in almost every governmental agency will all be lost if there is not some evidence soon of something new and something better for the retardates in the thousands of communities across this Nation.

Now is the time to develop broad and workable interagency relationships and inter- and intra-agency communications. Now is the time to develop simplified, standardized application procedures. The citizens' group in small areas may want to develop facilities for their retarded. How can they hope to compete with the large cities or the State agencies that have knowledge and experience in grantsmanship? The present complicated structure and chain of command by which applications must be brought, and by which they must be processed will, in far too many States, benefit those who have and bypass those who have not the administrative manpower to write the application and push it through channels.

Is there any valid reason that the many agencies and their several branches cannot work cooperatively, concurrently, closely, and cordially on the many parts and on the whole of this problem? Is it impossible to develop a simplified application for the smaller facilities and for the smaller programs where the Federal investment will be minimal compared to the amount in the total program? After all, when the funds have been really divided there won't be many large grants provided the small areas.

The national action to combat mental retardation calls for a bold, new approach in many areas. What we have done and are now doing for most of the retardates in this country is too often too expensive because it is too often limited to diagnosis and institutional placement, or to diagnosis and return to the home. Such a warehouse approach does nothing to salvage the ability that many retardates have or may be helped to develop. They spend their lives as takers, not contributors, and that is too expensive a way to handle the problem.

We must try new ways. We must develop better techniques. In order to do new things the people responsible for putting the Federal funds into the action programs and facilities must be willing to be flexible and receptive to new concepts. They must be willing to modify existing regulations and guidelines, even policies, for some of the more progressive experiments in programing and construction, if such a need arises.

Those who establish policy and procedure in each of the Federal, State, and local agencies involved in this all-out attack on developmental retardation must take the lead in establishing interagency and intra-agency cooperation and coordination.

Be assured that hyperspecialization and over-complication of the application for, and the disbursement of, the rather limited funds that will be available to any given local level will stall, if not abolish, many local efforts to do something new and something meaningful and something better for the developmentally retarded in the United States.

EDITOR'S NOTE: In comments following Dr. Hinman's talk, the Program Moderator, Dr. Graning, indicated that the concern expressed by Dr. Hinman for maximum interagency cooperation is shared by the operating agencies of the Department of Health, Education, and Welfare, and by State agencies. He noted that such cooperation prevails within all portions of the Department of Health, Education, and Welfare, and that reports from State agencies indicate there is extensive cooperation.

COMPREHENSIVE PLANNING UNDER P. L. 88-156 AND RELATIONSHIP TO PLANNING UNDER P. L. 88-164

Paul H. Pearson, M.D.
Chief, Mental Retardation Branch
Division of Chronic Diseases

The mental retardation planning grants to the States were authorized in Section 5 of the "Maternal and Child Health and Mental Retardation Planning Amendments of 1963," Public Law 88-156. An appropriation of $2.2 million was made available to be used by the States for planning comprehensive action to combat mental retardation.

These planning grants were an important first step in implementing many of the recommendations of the President's Panel on Mental Retardation, particularly those directed to planning, organization, and coordination of State and local services.

The President's Panel Report was notable in that it reflected the panel's deep conviction that services for the mentally retarded provided by State and local agencies must be coordinated in their administration and comprehensive in their scope.

The authorizing legislation directed the purposes for which grant funds ould be used to the following:

1. To determine the action needed to combat mental retardation in the tates and the resources available for this purpose.

2. To develop public awareness of the mental retardation problem and f the need for combating it.

3. To coordinate State and local activities relating to the various spects of mental retardation and its prevention, treatment, or amelioration.

4. To plan other activities leading to comprehensive State and community action to combat mental retardation.

This legislation authorizing grants for planning comprehensive action is gnificant not only because it provides the means for the States to develop a lueprint for the long-range attack on this problem, but also because of its ecognition of the need for true interagency and interprofessional coordination n this type of planning.

Nevertheless, even the establishment of an interagency coordinating ody may not assure participation of all programs with major mental retardation esponsibility. Program areas such as vocational rehabilitation, maternal and hild health, mental health, and crippled children's services all have a vital ontribution to make in coordinated services but are often the responsibility f a subdivision within a broader State agency, and therefore may not be ffectively represented on interagency bodies.

This points up the important duty of the State comprehensive planning ody and of the executive departments represented on it to identify, first, he generic settings serving societywide needs for health, education, welfare, nd justice which can be stimulated to give expert services to the retarded.

Second, these bodies must identify those specialized services needed niquely by the retarded. Together, they form the totality of the "array of ervices" discussed in the President's Panel Report on Mental Retardation.

The differentiation of general and specialized services is vital not only o ensure maximal use of resources, but also to answer the practical question f utilizing Federal construction money. Since this money is available only or "facilities especially designed" for the retarded, these Federally aided acilities will constitute but a fraction of those needed.

Since these facilities are vehicles for services, it is of great importance that the State plan for facilities reflect the findings and program projections developed by the State body having overall responsibility for comprehensive planning.

Because comprehensive planning and facility planning are established in separate Federal statutes, responsibility for integrating the plans at the State level rests heavily on State initiative. In fact, integration and coordination of these two plans was required for Federal approval of the State's comprehensive mental retardation planning grant.

Believing that we should practice what we preach, the following steps have been taken to implement coordination at the Federal level. First, initial guidelines for the comprehensive planning grant were developed by the Interagency Departmental Committee. If you have not already obtained copies of these guidelines, we will be glad to furnish them to you.

Second, all State applications for this comprehensive planning grant were reviewed by an Interdepartmental Committee composed of agencies in the Depart ment of Health, Education, and Welfare which had programs in mental retardati plus agencies in the Department of Labor and the Department of Interior.

The Division of Hospital and Medical Facilities has been represented by Mr. Almack on the Interdepartmental Review Committee for reviewing applications by States for grants for comprehensive planning to combat mental retardation.

There is continuing consultation between the staffs of the Mental Retardation Branch of the Division of Chronic Diseases and the Division of Hospital and Medical Facilities, on the progress of both activities.

Coordination at the Federal regional office level has been carried out through the interagency regional committee on mental retardation. Representati from the Division of Hospital and Medical Facilities have been included on alm all regional office mental retardation committees. Most of the regional offices are continuing their Interagency Coordinating Committees on Retardation, at lea through the period of planning.

When States express problems or raise questions with regard to coordination of the two planning activities, representatives of both Divisions should provide joint consultation to the State.

In regard to coordination at the State level, representatives of the State agency responsible for construction of mental retardation facilities should be included on the State Comprehensive Planning Committee. And we, in approv of a State plan, insisted that they be included as active participants in the development of comprehensive planning activities.

Staffs responsible for mental retardation facilities and comprehensive planning should obviously be in full contact with one another and confer regularly.

The development of a State plan for construction of mental retardation facilities and comprehensive State planning to combat mental retardation should proceed concurrently. It will be necessary for the first year construction plan to be submitted while the comprehensive planning activities are still under way. This immediately poses a problem which can be solved only by close cooperation between these two groups.

We have asked that the State Comprehensive Planning Committee give priority to those aspects of the planning which relate to the State plan for construction of facilities. Priority should be given to assisting in the collection of data and the gathering of information for the inventory of services and facilities required in Public Law 88-164. The comprehensive planning group should address itself to consideration of those policy matters, recommendations, and setting of goals which relate to the setting of priorities for the construction of mental retardation facilities.

Both planning groups will be gathering data pertinent to their respective planning activities. Whenever possible, arrangements should be made for joint collection and sharing of data.

The comprehensive plan must consider the broad issues and philosophies by which the State will develop its services to the retarded. This must provide the basis for the State plan for mental retardation facilities construction. Obviously, both are parts of the same whole.

The grants for planning comprehensive action to combat mental retardation were designed for a specific purpose: To enable the States to intensify their planning for the retarded and provide the impetus for a fully coordinated interagency approach.

We hope that the cooperation and communication established during this intense planning experience will result in a climate of improved interpersonal relationships, increased familiarity with one another's programs, and an on-going process of team work between the various State agencies. This is imperative if we are to solve the complex problems ahead of us and achieve full justice for the mentally retarded.

CONCEPTS OF A STATE PLAN FOR THE CONSTRUCTION OF FACILITIES FOR THE MENTALLY RETARDED

Mr. Ronald B. Almack
Chief, Community Facilities for the Mentally Retarded
Division of Hospital and Medical Facilities

My discussion will be devoted primarily to the basic concepts involved in developing a State plan for construction of facilities for the mentally retarded. We all know the importance of the State plan as the document containing the principles, guidelines, and factual information essential to effective implementation of formula grant construction programs. For many of you who have been associated with the Hill-Burton program over the years, a large part of what I have to say will be familiar. The differences which you will detect are related to the manner in which the concepts must be spelled out in the area of mental retardation in contrast to the area of hospitals and related health facilities.

Some of the concepts I want to discuss briefly are related to the nature of mental retardation described by Dr. Hinman. Others are related to current thinking in the field of mental retardation. Still others are inherent in the planning process. In terms of the nature of mental retardation and its effect upon the totality of the individual, there are two basic planning concepts to consider. First, a variety of services will be necessary to meet the total needs of the mentally retarded. In many instances, the retarded individual will use more than one service, sometimes more than one service at one time. The second concept is that an array of services must be available to provide a continuum of care.

If we recognize that the prime goal of services for the retarded is to provide opportunities for the retarded individual to attain his fullest potential, then utilization of family and community resources is most desirable. From this objective stem two additional planning concepts. One is the availability of community services for the retarded and the degree to which the retarded participate in these services. This availability and participation must then be evaluated in terms of the extent to which the total needs of the retarded are being met. The other concept is that specialized services should be developed on a community basis so that family and community resources can be appropriately utilized.

We are familiar, of course, with the importance of inventorying existing services and facilities in the development of a State plan for the construction of facilities. The inventory provides quantitative data essential in the programing of additional services and facilities. Therefore, an effective inventory is basic to good planning.

In the formula grant program for the construction of facilities for the mentally retarded, planning must be related to specific definitions which have been spelled out in the regulations pertaining to this program. In the programing of additional services and facilities for the mentally retarded, flexibility is essential. This is true because of the variety of services required by individuals with different potentials in different levels of retardation and age groupings. If we take this variety in individual potentials, services needed, levels of retardation, and age groupings and put down all the various possible combinations, we can readily understand the importance of flexibility.

The formula grant program also requires the establishment of service areas. An important concept in planning is that these service areas should be rather large in order to have meaning and significance and to avoid artificiality. The reason for encouraging the development or the delineation of large service areas is simple. The geographical territories covered by different types of facilities for the retarded will vary widely. For example, the area served by a day facility for training preschool-aged children will be different from the area served by a workshop. The area served by a diagnostic clinic connected with a medical teaching center will be different from the service area of a community residential facility. Hospital regions established for the Hill-Burton program may offer some basis for determining these large areas.

The last concept I would mention is the importance of judgmental factors. Judgmental factors are most important in planning for services and facilities because mental retardation involves the total individual. The needs of the total individual cannot be adequately met through decisions based solely upon statistical interpretations. Quantitative data must be backed by qualitative evaluations. In fact, in planning facilities for the mentally retarded, quantitative data serve primarily as background information upon which to base qualitative judgments.

We feel that if these concepts are given careful consideration they will be the foundation stones for the development of good planning for the construction of community facilities for the mentally retarded.

STATE ACTIVITIES AND PROBLEMS IN DEVELOPING A STATE PLAN

Mr. Bert W. Schmickel, Deputy Commissioner
Office of Mental Retardation, Connecticut Department of Health
Hartford, Connecticut

I have been asked to discuss the activities that have taken place in Connecticut and the problems we have encountered in implementating the new mental retardation construction program under Title I, Part C of P.L. 88-164. Inasmuch as we have already initiated our program, I would like to describe our activities to date in the hope that our experiences will be helpful to those of you who have not yet started to develop a statewide construction program.

Our first step was to become familiar with the new legislation and the regulations which govern its implementation. In doing this, extensive use was made of the document "Draft of Procedures and Forms for Developing a State Plan." We have come to think of this document as our bible to assist us in doing a proficient job of developing our construction plan.

The next step was to orient staff members assigned to implement the program. A meeting was held to carefully review all documents relating to this program: the legislation, the regulations, and the planning guide. Preparatory to this meeting, all salient factors in the planning guide were annotated and underlined.

Following several staff conferences, a concise outline of responsibilities was drawn up. This outline covered the relationship of the planning for the construction of facilities for the mentally retarded with the State plan for comprehensive services which Dr. Pearson has just
included a list of basic goals and objective
the procedures to be followed in making an inventory of existing services and facilities.

The inventory of existing services and facilities is now underway, and a mailing technique is being used for this. Each known facility has been sent a kit of three forms and instructions. Basically, these forms are the same as Forms A, B, and C contained in the guidelines for developing a State plan. In preparing the mailing list, several directories of facilities were used. Forms were sent to agencies having specific programs for the retarded and to known facilities in which 50 percent or more of the persons served were mentally retarded.

Inventory questionnaires were mailed to many agencies and organizations. ncluded nine vocational rehabilitation offices in the State, four institutions ng services for the cerebral palsied, five child guidance clinics, and different children's organizations. Since a number of residents in correc- institutions are retarded, it was deemed important to survey the four fa- in this category. The two Goodwill Industries, as well as 25 parent tions that conduct programs for the mentally retarded were also mailed ory forms. These latter facilities are provided financial assistance through ntal retardation program for Connecticut. In some cases they offer only care program, but there are also many facilities in which a comprehensive n is provided. Among the other organizations being contacted for infor- are the Mystic Oral School for the Deaf, the American School for the the Connecticut Institute for the Blind, five private nurseries, seven re- ation centers, and all State hospitals, training schools and regional centers retarded. State mental institutions were also mailed questionnaires.

To date, the returns indicate excellent cooperation. Although these nnaires have been out only for some nine or ten days, approximately 20 have already been received. At first the staff felt that, inasmuch as es get so many requests for this kind of information, these three detailed nnaires might be frightening, and that there might be some hesitancy on t of some organizations to complete and return them properly. However, received to date have been quite well done and some agencies have taken uble to telephone us in an attempt to clarify various types of questions and ns.

In delineating service areas we plan to utilize the 11 regions already hed for our State mental retardation program. These regions are closely to those developed by the Connecticut Development Commission. This sion has devoted a great many years to the study of various patterns of lization, and a great deal of information was already available for use development of our regional plan. Similar information may be available State to assist in setting up geographical service areas.

As a whole, we find, in these early stages, that the development of a lan is going very well. We are able to envisage our completed program l we will be ready to play our part as the administrative agency for the retardation construction program in Connecticut within a very short time.

INTERRELATIONSHIPS IN FACILITY PLANNING FOR MENTAL RETARDATION, COMMUNITY MENTAL HEALTH CENTERS, AND HOSPITAL AND RELATED MEDICAL FACILITIES

Mr. John D. Thewlis
Chief, Operations Branch
Division of Hospital and Medical Facilities

My remarks will be limited to administrative matters associated with the development of State plans for the mentally retarded, which is the foundation for implementing Part C of Title I of P.L. 88-164--grants for the construction of facilities for the mentally retarded.

First, it should be emphasized that P.L. 88-443, covering the new Hill-Burton program, and P.L. 88-164 are separate laws--yet are similar in many respects. Each provides for the development of State plans for the construction of health facilities. In more detail, each requires the designation of a State administering agency, an inventory of existing facilities, a programing of needed facilities and services, and the establishment of construction programs to meet the needs in the various areas throughout the State.

In regard to State agencies, a number of States have designated one agency for both programs; other States will have two agencies; and in some States there will be three different agencies administering the formula grant programs authorized under the two laws. This emphasizes the importance of coordinated planning activities. Every speaker thus far has stressed the need to provide some mechanism to assure coordination and cooperation in planning, especially at the State level and, of course [illegible] Washington and in our regional offices. I might emphasize [illegible] programs are not mutually exclusive. For example, there has been much discussion regarding the extent to which a psychiatric unit in a general hospital could receive aid under the Hill-Burton program. P.L. 88-164 also includes Federal aid to assist in constructing inpatient facilities, especially in the community mental health center program.

How can these interrelationships be established at the State level? There was considerable discussion of this problem yesterday in the committee meetings. One suggestion was the development of some sort of interagency planning committee concerned especially with the collection of data and the development of State plans. Since no project may be approved unless it is programed in the State plan or plans, coordinated planning is essential.

Another problem is associated with the joint funding of projects because f the limitation of funds authorized under some of the programs. This is a istinct possibility, since a project or elements of a project may be eligible nder two or three of the programs. Again, this calls for coordination.

A final point, and one which Dr. Pearson referred to, is that of timing s it is associated with State planning under P.L. 88-164. Funds were appro- riated by the Congress for construction purposes in 1965. These funds are vailable for two years. We are now roughly 6 months into the first year of ne availability of these funds. I have found in discussions with the various tate agencies that State planning under P.L. 88-164 will delay the approval f projects until the second year of availability of these funds.

In this regard, I would suggest that those agencies which have not had xperience in the administration of construction programs discuss with the Hill- urton agency the problems of developing projects, bringing them to the point here you can encumber funds in the second year.

It takes from 8 to 12 or 16 months to develop construction projects. nder the law this means the project is ready to go under construction. I oint this out only because I think it is very important that there be established the State level cooperation in planning, in programing, and in working to- ether in terms of developing the State plan and utilizing the knowledge and ill of all persons who can assist in assuring the development of the best plans nd programs possible.

COMMENTS ON PANEL DISCUSSION

Stafford L. Warren, M.D.
Special Assistant to the President on Mental Retardation
The White House
Washington, D.C.

I have only a few comments. First, I would like to mention that it is unfortunate that the complexities of administration make it impossible for us to have a single contact at either the State or Federal levels. As one of the panel members has said, there may be as many as three agencies in the State concerned with the mental retardation program and the organization of State construction plans. However, I think we will be able to find ways to cope with this problem so the program can be made operable.

The big problems you will face relate to the completion of State plans, the allocation of priorities, and meeting deadlines for submitting State plans. I hope those of you who have to administer this program at both the State and Federal levels will appreciate the fact that you can't get a perfect plan, ever, or even one that will ever be quite finished.

It seems that there are so many gaps, so many critical, crying needs throughout communities everywhere that the most obvious gaps will have to be filled first--the ones that will have the greatest impact on lead time, on waiting lists, and those filling the greatest needs.

The strictly medical and public health aspects of mental retardation are generally solved in infancy or in the preschool period. After that, retardation is a problem of education and training, something with which the medical profession needs more direct contact to assure better services to the retarded. Recently, there have been surprises and successes from new approaches and additional efforts. I hope that you will remain flexible and that you will also try to encourage your physical facility planners to be flexible in order to accommodate these new approaches as they demonstrate their usefulness.

In encouraging flexibility, I think that recreational facilities must be considered for those people who are going to be in residential and day care situations for long periods of time. Athletic activities and other outdoor environmental influences are not only emotionally satisfying but can contribute greatly to the development of better muscular coordination, group participation and many other desired achievements. These are very important. Great strides can be made if recreational facilities can be fully considered.

Finally, one of the things often found lacking is provision of enough staff offices for new personnel and enough educational and rehabilitation space.

The task that lies ahead presents many challenges. In fulfilling our various responsibilities, let me join with others who have preceded me on today's program in urging upmost cooperation in developing programs and carrying out activities which are all directed toward a common goal.

ARCHITECTURAL GUIDELINES FOR ELEMENTS AND SERVICES OF FACILITIES FOR THE MENTALLY RETARDED

Mr. Wilbur R. Taylor
Deputy Chief, Architectural and Engineering Branch
Division of Hospital and Medical Facilities

We have been engaged in this unique job of developing guide material for various types of health facilities for some time and I assure you it is a real challenge. This is our first assignment on a broad scale in the area of mental retardation, and we are finding that many lessons learned in the past have direct application for us in this latest endeavor. For example, experience has taught us that an essential consideration in developing effective design for health facilities is an understanding of the philosophy and policies governing the programs being carried out. From this standpoint, we are off to a good start since we were able to incorporate in our planning the philosophies of various groups such as the American Association of Mental Deficiency, the National Association for Retarded Children, the Office of the Special Assistant to the President on Mental Retardation, outstanding authorities on the subject, and the professional skills in the Public Health Service and other agencies of the Department of Health, Education, and Welfare. Emphasis in this program is placed on small facilities that will meet demonstrated needs in the local communities rather than on large centralized State institutions. Smaller, possibly specialized facilities, can be located conveniently for a limited population area and permit closer community orientation and interaction.

Since the pattern of care for the mentally retarded varies from community to community and from State to State, it would not be feasible to try to develop a prototype. However, there are certain fundamentals that can be incorporated in guidelines, and I have a table and several figu

Similarly, an educational and training building for the mentally retarded requires specific areas for noisy activities, classrooms that may be used interchangeably, and multipurpose rooms. The size of the classrooms for the mentally retarded may be the same as that for a public school room; however, since classes are smaller, there is more space per pupil. The need for storage space for equipment and supplies for the mentally retarded is greater than that required for a public school classroom. Also, toilet facilities nearby, preferably adjoining the room, are essential for the classroom for mentally retarded children.

ENVIRONMENT

Many facilities in use today are in poor repair and ill-suited for the purpose. They have areas with limited daylight as well as poor lighting and are dingy and run-down in appearance. Since educating and training of the mentally retarded are difficult tasks, we need space and environment that will help our instructors rather than handicap their efforts.

Esthetics is a functional requirement. The environment should be one replete with color, properly used, and should express warmth, intimacy, and attractiveness in an atmosphere that provides a living experience--one that makes the student eager to return. In this sense, the provision of proper surroundings is an essential part of therapy.

PROGRAM

Before an architect can design a facility, a written program is necessary. This program will explain the functions to be performed, the number of staff and students involved, the equipment necessary, and the required space relationships.

Without such a document, an architect cannot develop an adequate plan since the design should be based on the program. The importance of such programing has been long recognized by manufacturers who have a particular interest in the efficiency of production which is reflected in the cost of the product. Once the architect has been provided the details of the production flow and personnel requirements he can then design the building around the necessary workflow. Later, if the flow is changed and the confines of the building handicap production, alterations are made. In the health field, we have not approached such proficiency. Instead, we often find ourselves compromising or adapting our functions to fit within an existing building that does not permit proper relationship of areas and may have insufficient space for the functions performed.

The Table and Figures 1-7 are based on preliminary studies of plans for certain types of facilities and will serve as guides for further development. We expect to publish more complete plans with text describing these facilities together with the program functions to be carried on in each facility.

TABLE. ESTIMATES OF RETARDATION BY AGE AND DEGREE

The information in this table is familiar to most of you and indicates only approximately the number of mentally retarded in the various categories. These are national figures and cannot be related to an individual community because of many factors. Therefore, before a building program is inaugurated, a careful survey of the area served by the community is essential to determine the potential number of mentally retarded in each category.

ESTIMATES OF RETARDATION BY AGE AND DEGREE* - 1963

	ALL AGES	UNDER 20 YEARS	20 YEARS & ABOVE
GENERAL POPULATION (1963)	189,000,000	73,000,000	116,000,000
3% MENTALLY RETARDED	5,700,000	2,200,000	3,500,000
1% MENTALLY RETARDED	1,900,000	700,000	1,200,000
RETARDED			
PROFOUND (IQ 20) about 1-1/2%	85,000	50,000	35,000
SEVERE (IQ 20-35) about 3-1/2%	200,000	100,000	100,000
MODERATE (IQ 36-52) about 6%	350,000	150,000	200,000
MILD (IQ 53+) about 89%	5,000,000+	2,000,000+	3,000,000+ (1 million +
TOTALS	5,600,000		

*From "Facts on Mental Retardation," Association for Retarded Children,

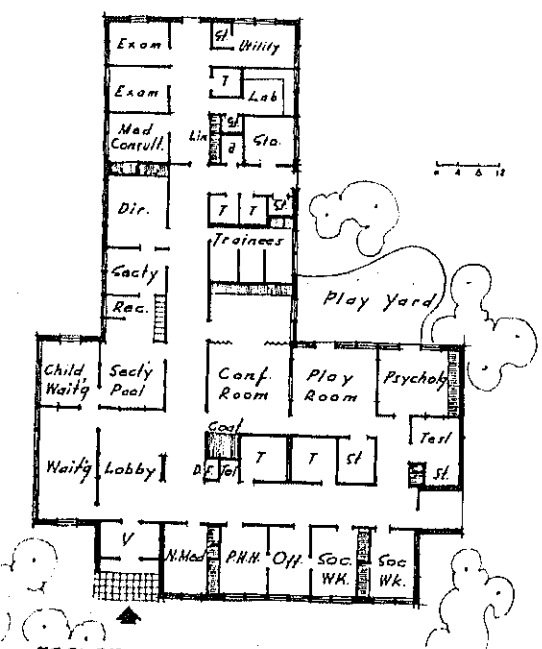
FIGURE 1. DIAGNOSTIC AND EVALUATION CENTER

In accordance with P.L. 88-164, PHS Regulation, Section 54.104 (b)(2), facilities for the provision of diagnostic services (see paragraph (a) of this section) shall be planned to serve an annual caseload of not less than 150 or more than 300 retardates.

This suggested plan of a diagnostic and evaluation center provides facilities for approximately 150 new cases annually plus 350 follow-up cases for a total of approximately 500 cases per year. If determination of caseload were made on a basis of approximately 3 percent of the annual birth rate, then the figure would be slightly less than 150 new cases. However, provision should be made for diagnosing more than this number since frequently there are mental retardation suspects who may be found to be handicapped for other reasons.

This facility was developed from data supplied by the Children's Bureau and other sources which indicate that a staff of approximately 7-1/2 full-time personnel is required for the above-mentioned caseload.

The column headed "Elements" lists the basic spaces needed. It is assumed that as a result of proper scheduling consultants will be able to use certain offices interchangeably.



ELEMENTS

Director's Office
Secretary's Office
Medical Consultants
Examination Rooms (2)
Specimen Laboratory
Psychologist's Office
Test Room
Playroom
Outdoor Play Yard
Social Workers' Office (2)
Public Health Nurse
Nonmedical Consultants
  Nutritionist
  Vocational Counselor
  Educational Counselor
  Others
Conference Library
Trainees' Office
Secretarial Pool
Waiting-Toilets
Children's Waiting
Janitor-Storage
Unassigned Office

SUPPLEMENTARY D & E SERVICES

Laboratory
Speech and Hearing
Ophthalmology
Radiology
Dental
ENT
EEG

FIGURE 1. DIAGNOSTIC AND EVALUATION CENTER

(Annual caseload approximately 150 new cases and 350 follow-up cases)

The services listed under "Supplementary D&E Services" would be obtained elsewhere and evaluated in this facility.

Although any building shape may be satisfactory, this "L" shape was adopted because it provides a logical relationship of elements. The director's office is accessible through the secretary's office and is located so that it is not visible from the front door or public waiting room. One wing is provided for the director's office, medical examination rooms, and a small laboratory (for routine testing only), while the other wing houses closely related services. Note that the conference room is located conveniently for all who may use it and that it overlooks the playroom and play yard for easy observation of children at play. Similarly, the psychologist's office is also strategically located.

Teaching other professions is an important function in this service. Although most training will be done in the various offices, desk space is provided at the three cubicles marked "TRAINEE."

The waiting area for children is located where they can be supervised while parents are being interviewed. Separate toilet facilities are provided for visitors and staff.

This building could be freestanding or could adjoin an existing facility such as a hospital or other health related facility.

FIGURE 2. EDUCATION AND TRAINING CENTER - Approximately 100 students
6 - 16 years

This facility is intended primarily for the mildly and moderately retarded.

Administrative and consultative offices are at the extreme right, accessible from the lobby. The sick room is included for emergencies, which are possibly more frequent than in normal schools. This room may be required by some of the students for short periods of isolation and rest.

The girls' training area for socialization and daily living activities contains the usual facilities of bedroom, small kitchen, and living room. In addition to socialization, training activities anticipated here may include sewing, bedmaking, cooking and serving a meal, and household functions.

The training area for the older boys is primarily for woodworking, metal shop, and other noisy activities. Although this facility is not intended as a sheltered workshop activities similar to those in such a facility may be performed here. If desired, some prevocational testing could be done in this area.

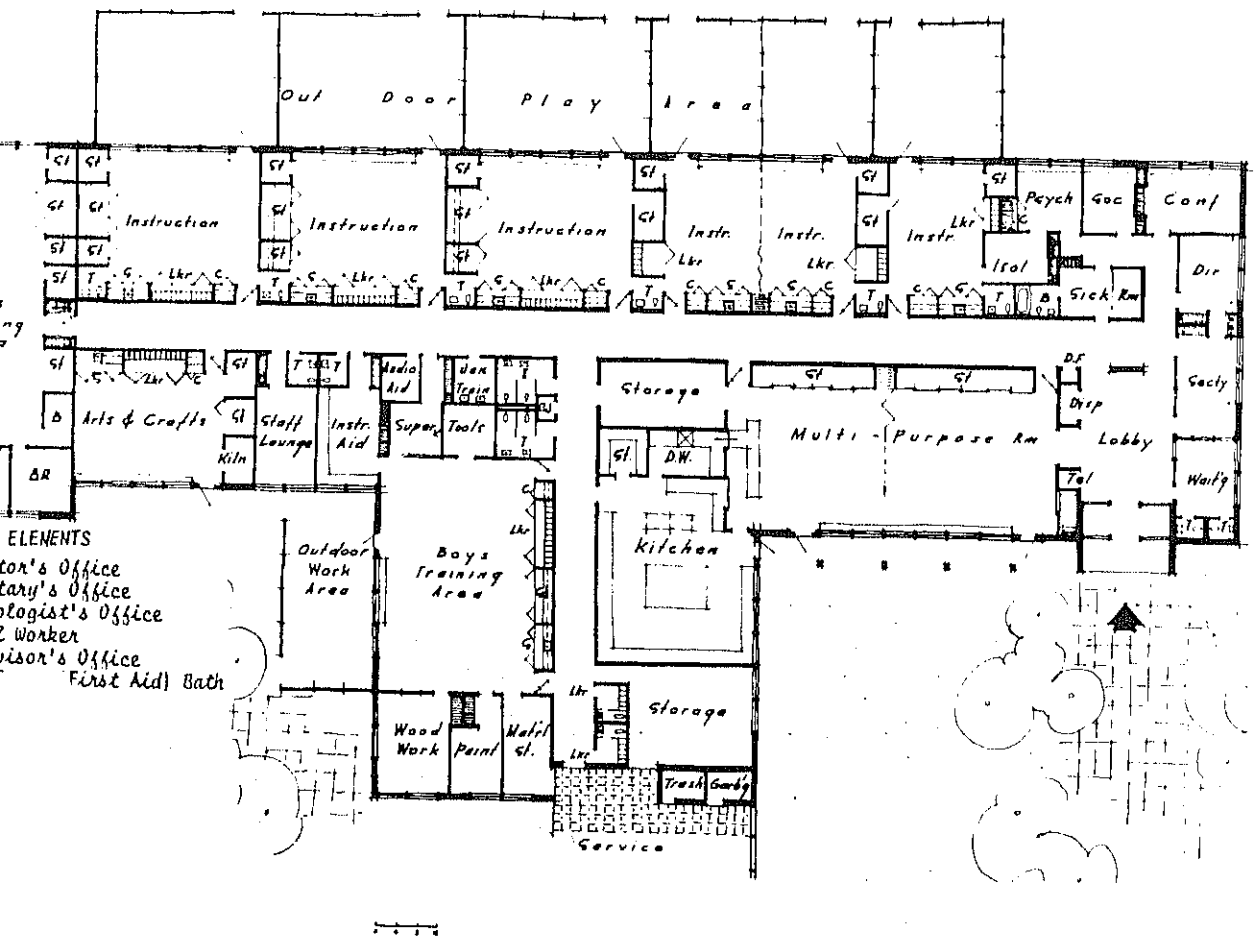


FIGURE 2. EDUCATION AND TRAINING CENTER

(For 100 students 6-16 years of age. Approximate total area 20,000 square feet)

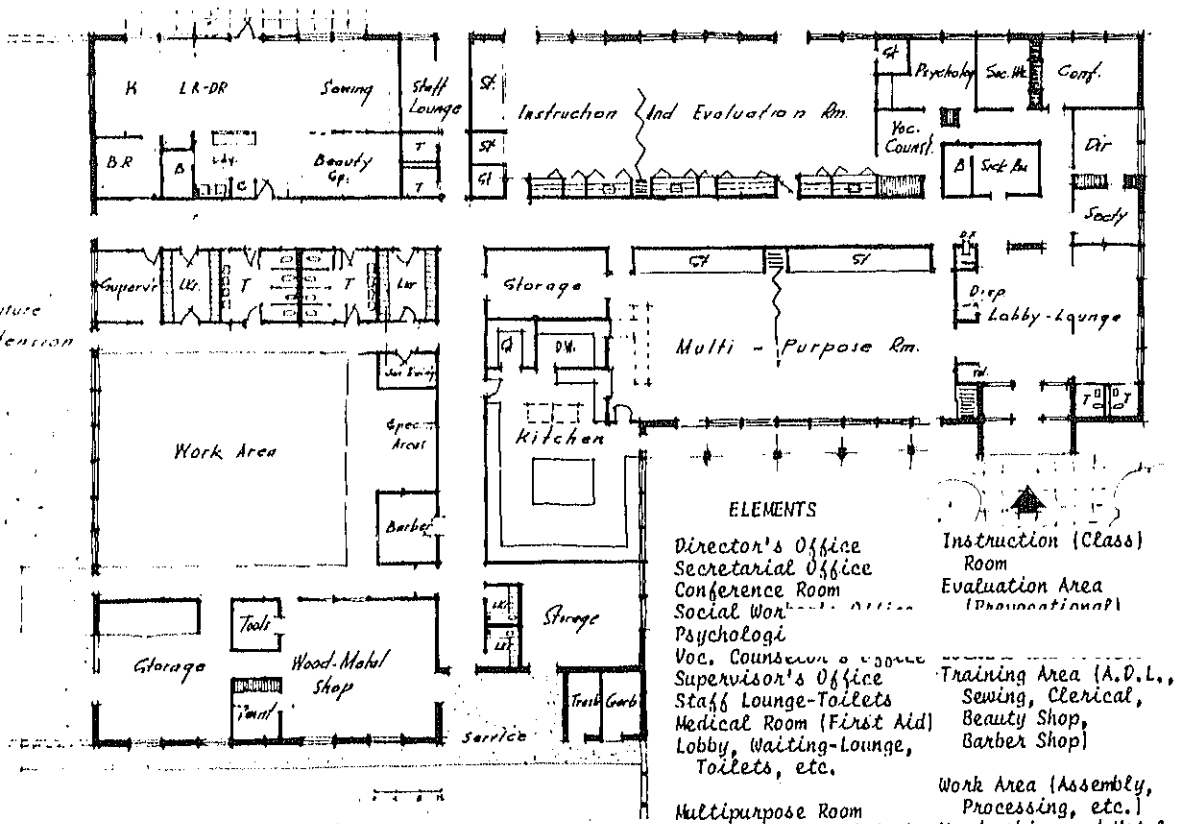
The layout of the arts and crafts room is the same as that of the other classrooms. Although arts and crafts activities will be done in other classrooms as well, it may be desirable to devote some space specifically for this function.

The workroom is for instructors to use for the preparation and storage of the ingenious equipment and instructional aids they design and make.

All activity rooms have access to the outside since many activities can be performed in outdoor play areas.

FIGURE 3. ADULT TRAINING CENTER - Approximately 100 students

This adult training center is physically similar to a sheltered workshop. It is used to train adults who may work in private employment or in a sheltered workshop. The main area should be a large unpartitioned space suitable for multipurpose functions. If activities that produce dust, excessive noise, or



ELEMENTS

Director's Office
Secretarial Office
Conference Room
Social Worker's Office
Psychologist
Voc. Counselor's Office
Supervisor's Office
Staff Lounge-Toilets
Medical Room (First Aid)
Lobby, Waiting-Lounge, Toilets, etc.

Multipurpose Room (Dining, Activities)
Kitchen-Dishwashing
Storage-Janitor
Trash Room
Garbage Room
Service Area

Instruction (Class) Room
Evaluation Area (Rehabilitational)
Training Area (A.D.L., Sewing, Clerical, Beauty Shop, Barber Shop)

Work Area (Assembly, Processing, etc.)
Woodworking and Metal Shop
Finishing Room (Painting)
Storage
Loading Dock

FIGURE 3.

ADULT EDUCATION AND TRAINING CENTER

(For 100 students 16 years of age and older. Approximate total area 18,000 square feet)

possible hazards (such as paint spraying), are anticipated, partitioning will be necessary. However, division of space can be made by using storage cabinets or lockers to provide separation when desired. Some areas do need partitioning for privacy as indicated on the plan. The column on the right indicates the desired elements.

Plenty of storage space is a fundamental requirement and there should be a trucking platform nearby. It is well to plan for expansion since these programs, when successful, always need expanded facilities. The area here is approximately 11,000 square feet for 100 students although the area per person may vary depending on the types of programs to be carried out.

Fire resistive construction, good daylight, and electrical illumination, as well as sufficient electrical outlets and adequate heating and ventilation, are necessary.

FIGURE 4. SHELTERED WORKSHOP

This plan is similar to the plan in Figure 3, except that the area has been increased to approximately 15,000 square feet. This increase of approximately 40 square feet per person is primarily in the production area. The principles which apply for the design of a training center also apply here.

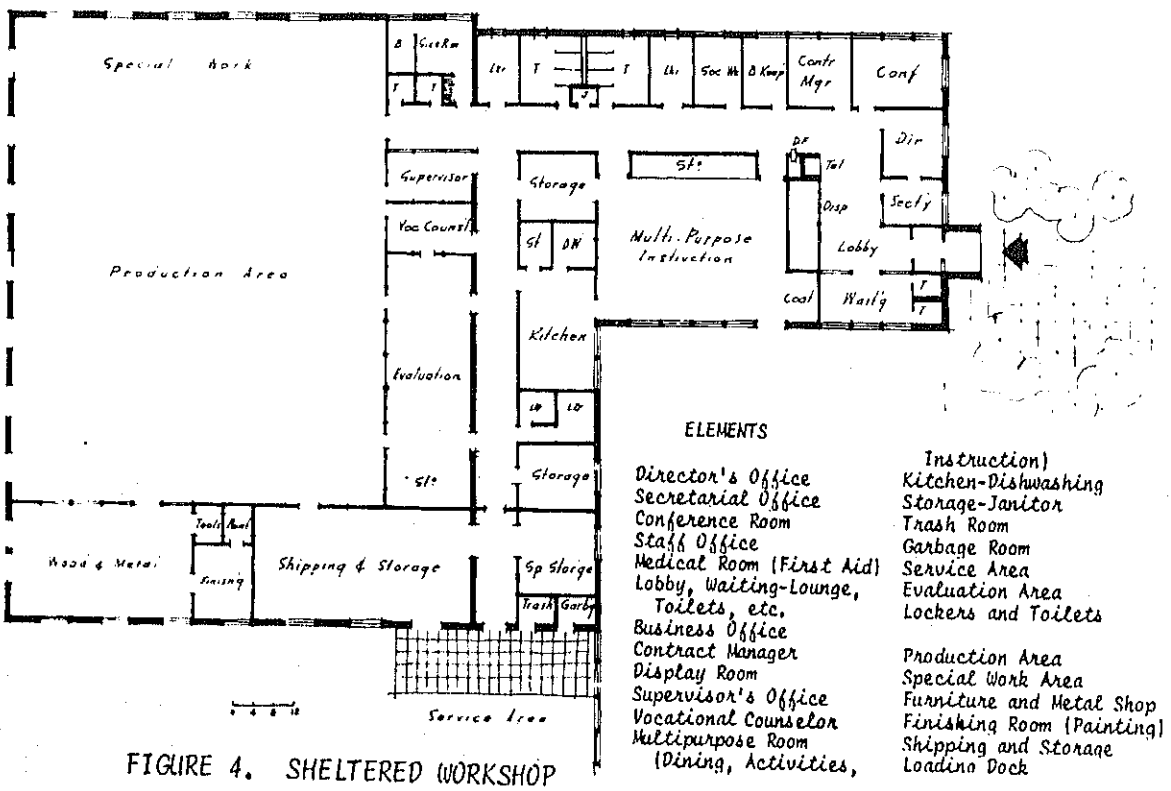


FIGURE 4. SHELTERED WORKSHOP

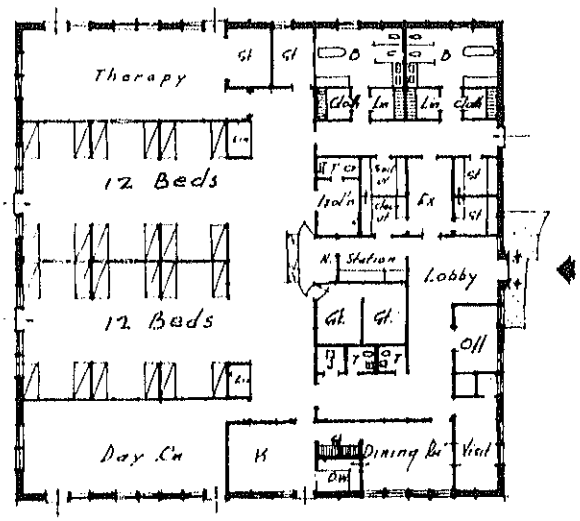
(For 100 employees. Approximate total area 25,000 square feet)

FIGURE 5. INFIRMARY FOR 20 BEDS

This facility could be located separately in a community or could be part of a 24-hour care facility providing more comprehensive services. However, if the patients require active medical attention, perhaps it should be located in close proximity to or on the grounds of a facility providing skilled medical care.

The shape of the building is unimportant as long as the relationship of the elements is satisfactory.

The important space relationships to the bed areas are the nurses' station, bath, day room, and therapy area. The location of the other elements are of secondary importance.



ELEMENTS

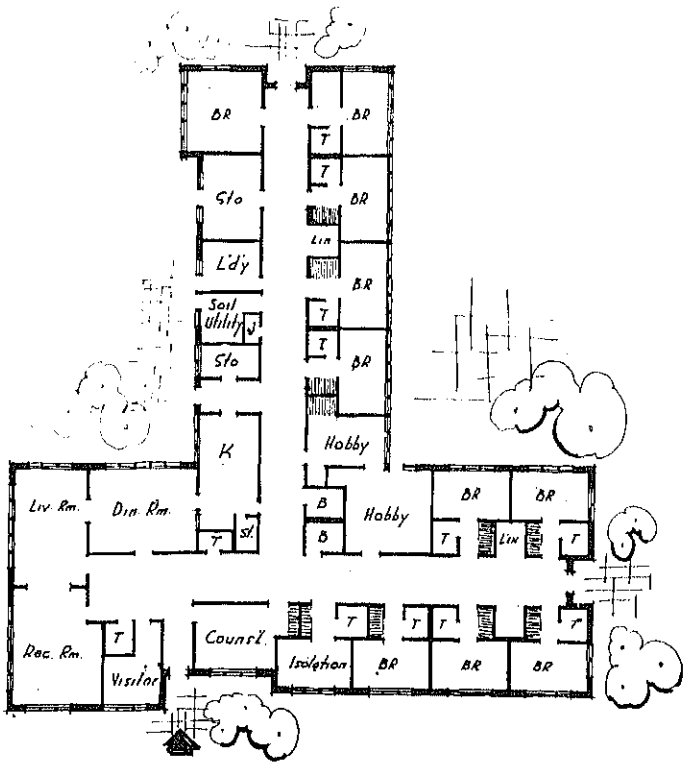
Patient Bed Area
Nurses' Station
Supervisor's Office
Visitor's Room
Examination Room
Isolation Room
Utility Room
Janitor
Clothing Storage
Soiled Holding Room
Baths and Toilets
Dining
Kitchen-Dishwashing
Waiting Area
Day Room
Therapy Room
Storage Rooms
Outdoor Play Area

FIGURE 5. INFIRMAR

(Approximate total

FIGURE 6. LIVING UNIT FOR 20 RESIDENTS

This unit should preferably be located in the residential area of a city although it may be placed on the grounds of a larger facility. It is intended for employed retardates who need only occasional support from a knowledgeable person in charge of such a residence. The environment is that of a residence and the type of rooms are the same, except that visitors' room and a private counseling room have been added. There is nothing magic about the number of 20. However, large units tend to lose the family atmosphere.



ELEMENTS

Living Room
Dining Room
Recreation Room
Hobby Rooms
Visitors' Room
Counselor's Office
Kitchen-Storage
Laundry Room
Soiled Holding Room
Bedrooms
Isolation Room
Baths and Toilets
Storage

FIGURE 6. LIVING UNIT FOR 20 RESIDENTS

(Approximate total area 7,000 square feet)

FIGURE 7. ELEMENTS OF A FACILITY FOR MENTALLY RETARDED - 24-HOUR CARE

This is a complex institution similar to many existing full-time care facilities. We do not intend to develop a prototype of this plan. However, we may develop some of the components as guides.

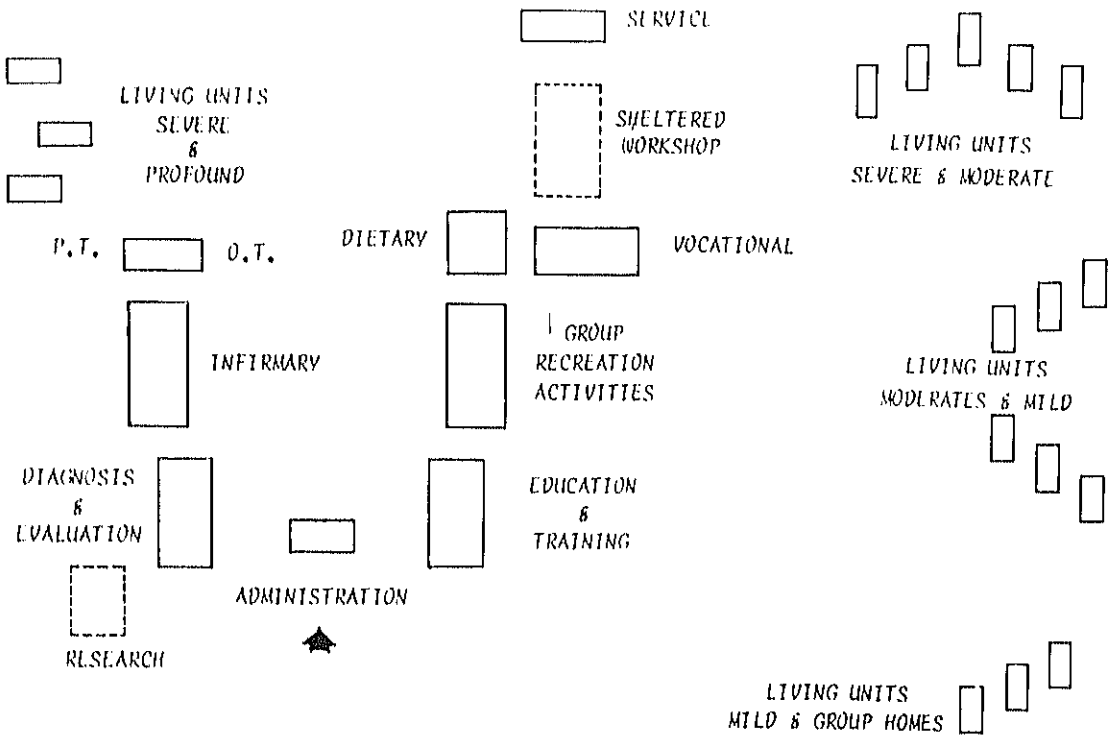


FIGURE 7. ELEMENTS OF A FA

(24-hou

RECOMMENDATIONS

The State and Territorial Hospital and Medical Facilities Survey and Construction Authorities recommend:

1. CONSUMER REPRESENTATIVE REQUIREMENTS RELATIVE TO STATE HOSPITAL ADVISORY COUNCILS

   That the Public Health Service reconsider its definition of the term "consumer" as it applies to membership on a State Hospital Advisory Council. A prospective member's primary interest should be the deciding factor in determining whether he is a consumer. The State agency should be responsible for making this determination.

2. SERVICE AREA DELINEATION

   That the Public Health Service amend the Hill-Burton regulations to permit some latitude in giving additional time to the States to comply with the requirement for delineating common service areas for general hospital and long-term care facilities.

3. RESPONSIBILITIES OF STATE AGENCIES FOR AREAWIDE PLANNING GRANTS

   That State agencies which have State funds available in excess of the amount required to obtain financial assistance for administrative purposes under Section 606 (c) of P. L. 88-443, be permitted to use such excess funds for matching special project grants for areawide planning.

4. CONSTRUCTION OF ACUTE PSYCHIATRIC FACILITIES IN GENERAL HOSPITALS

   That the Public Health Service seek a mechanism under the Hill-Burton program which will permit the construction of acute psychiatric facilities in general hospitals regardless of whether they are related to comprehensive mental health centers.

5. DEFINITION OF MAJOR REPAIR

   That the Public Health Service consider the possibility of amending the regulations establishing a sliding scale formula for the definition of "major repair."

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Edward H. Forgotson, M.D. - White House Staff, Deputy Special Assistant to the President for Mental Retardation

Mr. Wallace K. Babington - Office of the Secretary, HEW, Executive Vice-Chairman of Secretary's Committee on Mental Retardation

Paul H. Pearson, M.D. - Chief, Mental Retardation Branch, Division of Chronic Diseases, PHS

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Robert L. Smith, M.D., Regional Health Director, and Mr. Seldon H. Martin, Acting Program Director

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